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Citizenship according to the UNCRPD and in practice: a plea for a broader view

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ABSTRACT

This article relates the eight Guiding Principles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) to both liberal and relational perspectives on autonomy and different layers of citizenship. While the UNCRPD covers a broad scope of citizenship, accounting for liberal and relational values of autonomy, it appears that the recent long-term care reforms in the Netherlands primarily address outcomes based on liberal values. As a consequence, persons with long-term cross-domain care needs face barriers that threaten their citizenship in terms of access to adequate care and support services. We argue that long-term care and support services need to explicitly address the relational aspects of autonomy to warrant the citizenship of persons with disabilities.

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UNCRPD and autonomy

In 2016, the Netherlands ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The UNCRPD is a civil rights act, embedding citizenship for people with disabilities, and is built on eight Guiding Principles¹ (GP): (1) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; (2) Non-discrimination; (3) Full and effective participation and inclusion in society; (4) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; (5) Equality of opportunity; (6) Accessibility; (7) Equality between men and women; and (8) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities (Table 1). Together, these principles reflect the scope of citizenship and refer to two perspectives on autonomy.

Liberal autonomy refers to being a free self-governing agent who is independent from other people and makes choices without interference from

Table 1. Guiding Principles of the Convention related to liberal and relational autonomy and different layers of citizenship.

Guiding Principle	Liberal autonomy	Relational autonomy	Layers of citizenship
(1) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons	X	X	Political citizenship/full citizenship Democratic practice Identity Diversity Equality Barrier-free context
(2) Non-discrimination	X		(Exercising) Civil rights Formal status/juridical citizenship Identity Equality
(3) Full and effective participation and inclusion in society	X		Political citizenship/full citizenship Identity Contribution Belonging Barrier-free context
(4) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity		X	Democratic practice Identity Diversity Belonging
(5) Equality of opportunity	X		(Exercising) Civil rights Formal status/juridical citizenship Political citizenship/full citizenship Identity Equality
(6) Accessibility	X		(Exercising) Civil rights Formal status/juridical citizenship Political citizenship/full citizenship Identity Equality Barrier-free context
(7) Equality between men and women	X		(Exercising) Civil rights Formal status/juridical citizenship Political citizenship/full citizenship Identity Equality
(8) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities		X	Democratic practice Identity Diversity

others. From a liberal viewpoint, autonomy is perceived as a competence, something one can or cannot do. Relational autonomy, on the other hand, emphasises that autonomy is socially embedded and shaped by relationships with other people (Agich 1993); here, identity and interdependence are central constructs. Relational autonomy is an ongoing process of interacting with the environment, development, and being acknowledged as a valuable human being. These two perspectives on autonomy are not mutually exclusive; both need to be addressed in order to embed equal citizenship for persons with disabilities.

Since 'citizenship' is a complex construct, it is not easily understood. Among the nations that ratified the UNCRPD, care and support acts should facilitate full-scope citizenship of those who utilise these care and support

services. This article aims to elaborate on the different layers of citizenship and relate them to the GPs of the UNCRPD and the two perspectives on autonomy. Then, these insights are used to reflect on the actual practices of the recent long-term care reforms in the Netherlands and on the implications for adults with long-term care needs.

Citizenship

The UNCRPD refers both to liberal and relational perspectives on autonomy, and different layers of citizenship relate to key elements of the UNCRPD (Table 1). First, citizenship refers to civil rights and the ability to exercise them (GPs 2, 5–7). Albrecht (2006) calls this juridical citizenship. Citizenship also has a political connotation, which stresses the importance of ‘making a contribution’ to society. Contribution equals ‘full citizenship’, which implies optimal participation (GPs 1, 3, 5–7). Although persons with disabilities should be able to fully participate in social life, for example education, work, cultural experience, and social relations (i.e. inclusion), citizenship is often narrowed to employment (Brown and Patrick 2012). Here, citizenship is more of an outcome, a participation rate; that is, it attributes value to people who contribute to society in a specific way.

The Dutch Council for Public Administration described three layers of citizenship: formal status, democratic practice, and identity.² Citizenship as formal status is seen as an elementary dimension (GPs 2, 5–7). Equality is an important principle; society should be socially and physically accessible. Citizenship as democratic practice emphasises the mutual bond between citizens in a society (GPs 1, 4, 8). Citizens have a responsibility for living with each other, with all their differences, interests, and possible conflicts. Citizenship as identity concerns the way citizens want to participate in society and whether the citizen is acknowledged as an equal member of that society (GPs 1–8).

Citizens with long-term care needs emphasise the importance of belonging, being valued, and having agency. The Dutch Chronic Illness and Disability Council defines two pillars of ‘full citizenship’: equality (GPs 1, 2, 5–7) and diversity (GPs 1, 4, 8) (Wijnen and Baart 1998). These correspond to how citizens with, for example, a spinal cord injury define inclusion (van de Ven et al. 2005). Being part of society and valuable equal relationships are important themes (equality). In addition, self-realisation and exercising control are part of inclusion (diversity). In an Australian study, young adults with cerebral palsy were asked what citizenship meant in their life. Their responses yielded four themes: wanting to contribute to society (GP 3), inclusion (GPs 3, 4); equal opportunities (GPs 1, 2, 5–7), and a context without barriers (GPs 1, 3, 6) (Yeung, Passmore, and Packer 2008). Self-determination, participation,

and contribution were also mentioned by Morris (2005) as important concepts of citizenship articulated by people with disability themselves.

To conclude, apart from participation and juridical aspects of citizenship and being a self-determined agent (liberal autonomy), respect for identity and diversity and feeling part of the community (relational autonomy) are essential for citizenship. From this perspective, the UNCRPD is not only a juridical act but also includes being experienced as a valued human being, as well as respect for identity and diversity.

Long-term care needs and citizenship

In the Netherlands, youth with disabilities receive paediatric rehabilitation care. However, in adulthood, problems with health and participation become more prevalent as a person ages. For example, ageing with cerebral palsy concurs with an increased impact of the experienced limitations on daily activities (Benner et al. 2017).

Thus, care and support needs are dynamic and characterised by a gradual shift towards more intensified assistance in later life, or specific phases. These needs cannot be viewed in isolation from the context. In the Netherlands, the context of the social and support services has changed considerably since 2015. The long-term care reforms have substituted the entitlement to care and support for a statutory responsibility of care of local governments (Social Support Act 2015), health insurers (Health Care Insurance Act) and national government (Long-term Care Act), depending on the type of need and/or the severity of disability. For the Social Support Act 2015 and the Long-term Care Act, citizens with disabilities are expected to solve difficulties themselves and/or within their own social network, while access to care is based on strict inclusion criteria and a 'blind spot' exists for cross-domain needs. As result, about 25% of persons with disabilities have been confronted with extra barriers with regard to access to personal care and support services.³ The underlying problem is that the system focuses on liberal values of autonomy; that is, independence, (self-)agency, and self-reliance (Bredewold et al. 2018). Thus, the actual practice of the long-term care reforms in the Netherlands is at odds with Article 19b of the UNCRPD:⁴ 'Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community'. The practice violates two GPs that correspond to relational autonomy: 'Respect for inherent dignity, individual autonomy [...]' and 'Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity'.

This poses extra challenges for ageing citizens with long-term care needs to shape their citizenship. Older adults with long-term disabilities have expressed multiple concerns related to ageing, including health problems, having less energy to maintain their place in the community, restrictions in workability, and being meaningful for their social environment (Hilberink, van der Slot, and Klem 2017). The stacking of these cross-domain problems in health and community participation has considerable impact on one's fortitude and their network, in order to incorporate the long-term consequences of one's disability into a meaningful life. In fact, these disability-related consequences restrict the ability to uphold the role of a self-reliant citizen (Sandström 2007). Better access to care and support services is needed; however, this involves not only addressing care and support needs but also acknowledging that support is needed to maintain social roles. The lack or withholding of such an acknowledgement can lead to loneliness, and to feeling unvalued and invisible.

Conclusion

The UNCRPD refers to perspectives of both liberal and relational autonomy, and also relates to different layers of citizenship. The actual practice of the long-term care reforms aims at self-reliance and independence. This fixation on liberal values does not do justice to the full scope of citizenship of persons with disabilities; it neglects the social roles people have, their identity and ideals, being part of a context, and of a society.

We propose a shift in thinking about the care and support for people with long-term care needs. Firstly, neither care nor support needs are fixed in time, they are likely to increase and vary throughout a lifespan. Secondly, disability is 'embodied', in that is an aspect of one's identity. Therefore, instead of focusing on the outcomes of care and support, the challenge seems to be how care and support can contribute to one's citizenship in a broad sense. Of course, participation outcomes are important but, as mentioned, they are only one part of the entire picture. If we want people with disabilities to 'be included' in society, it seems necessary to explicitly address the relational aspect of autonomy in care and support (i.e. policies and practices) as well as how people with disabilities utilise these in order to play their role as a citizen. After all, this is the very heart of the UNCRPD.

Notes

1. See <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/guiding-principles-of-the-convention.html> [accessed September 18th, 2018]
2. See https://www.raadopenbaarbestuur.nl/binaries/raad-openbaar-bestuur/documenten/publicaties/2001/04/01/etniciteit-binding-en-burgerschap/Etniciteit_binding_en_burgerschap_Adviserapport_200104.pdf [accessed September 26th, 2018]

3. See https://www.scp.nl/Publicaties/Alle_publicaties/Publicaties_2018/Veranderde_zorg_en_ondersteuning_voor_mensen_met_een_beperking [accessed September 28th, 2018]
4. See <https://www.binnenlandsbestuur.nl/sociaal/opinie/columns/is-slechte-zorg-eenschending-van-mensenrechten.9588205.lynkx> [accessed October 6th, 2018].

Disclosure statement

No potential conflict of interest was reported by the author.

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